## The Advisory Committee on Heritable Disorders in Newborns and Children

## HRSA Headquarters - 5600 Fishers Lane, Rockville, MD 20852 (Pavilion) November 8-9, 2017

### DAY 1 Meeting Agenda: Wednesday, November 8, 2017

TIME	TOPIC	PRESENTER	
9:30 – 9:45 AM	<ul> <li>Welcome</li> <li>Roll Call</li> <li>Opening Remarks</li> <li>August 2017 Minutes</li> </ul>	Joseph Bocchini, MD Committee Chair Professor and Chairman, Department of Pediatrics, Louisiana State University  Catharine Riley, PhD, MPH Designated Federal Official Health Resources and Services Administration	
9:45 – 10:30 AM	Working Toward Newborn Screening Timeliness Goals	Joshua Miller, MPH Research Instructor, Colorado School of Public Health Data Specialist, NewSTEPs	
10:30 – 11:00 AM	Q&A and Committee Discussion Regarding NBS Timeliness Goals		
11:00 – 11:30 AM	PUBLIC COMMENTS		
11:30 – 12:30 PM	LUNCH		
12:30– 1:45 PM	Implications of Detecting Carriers Through Newborn Screening	Michael Watson, PhD, FACMG Executive Director American College of Medical Genetics  Aaron Goldenberg, PHD, MPH Associate Professor of Bioethics and Director of Research, Dept of Bioethics, Case Western Reserve University  Michele Caggana, Sc.D., FACMG Director, Newborn Screening Program New York State Department of Health	
1:45- 2:15 PM	SMA Evidence Review – Phase 2 Report	Alex R. Kemper, MD, MPH, MS Lead, Evidence-based Review Group	
2:15 – 2:45 PM	Q&A and Committee Feedback – SMA Evidence Review		
2:45 PM	ADJOURN		

	WORKGROUP MEETINGS
3:00 – 5:00 PM	Education and Training Workgroup
	Laboratory Standards and Procedures Workgroup
	Follow-up and Treatment Workgroup

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### DAY 2 Meeting Agenda: Thursday, November 9, 2017

9:30 – 9:45 AM  • Welcome • Roll Call  • Beth Tarini, MD, MS, FAAP Committee Member Co-Chair, Education & Training Workgroup  Co-Chair, Education & Training Workgroup  I leffrey P. Brosco, MD, PhD Committee Member Chair, Follow up & Treatment Workgroup  Committee Discussion  11:05 – 11:25 PM  Laboratory Standards and Procedures Workgroup Update  11:25 – 11:45 AM  Committee Discussion  11:45 – 12:45 PM  LUNCH  12:45 – 1:00 PM  Prioritizing 2018 Workgroup Activities  Sikha Singh, MHS, PMP Manager, Newborn Screening and Genetics Operations, Association of Public Health Laboratories  Adrienne Manning Division Director, Newborn Screening Connecticut Department of Public Health Lisa Kobrynski, MD, MPH Associate Professor of Immunology Section, Allergy/Immunology Section, Allergy/Immunology Joseph Bocchini, MD	TIME	TOPIC	PRESENTER		
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Catharine Riley, PhD, MPH   Designated Federal Official, Health   Resources and Services Administration			Louisiana State University		
P:45 – 10:05 AM Education and Training Workgroup Update Education and Training Workgroup Update Education and Training Workgroup Update Co-Chair, Education & Training Workgroup Update ID:25 – 10:45 AM Follow-Up and Treatment Workgroup Update Chair, Follow up & Treatment Workgroup Update Chair, Follow up & Treatment Workgroup Update ID:25 – 11:25 PM Laboratory Standards and Procedures Workgroup Update Ex-Officio Committee Member, FDA Chair, Laboratory Standards and Procedures Workgroup Update ID:45 – 11:45 AM Committee Discussion ID:45 – 12:45 PM LUNCH ID:45 – 12:45 PM ID:45 – 12:45 – 12:45 PM ID:45 – 12:45			Catharine Riley, PhD, MPH		
9:45 – 10:05 AM			Designated Federal Official, Health		
9:45 – 10:05 AM Update Committee Member Co-Chair, Education & Training Workgroup  10:05 – 10:25 AM Committee Discussion  10:25 – 10:45 AM Follow-Up and Treatment Workgroup Update Chair, Follow up & Treatment Workgroup Update  10:45 – 11:05 AM Committee Discussion  11:05 – 11:25 PM Laboratory Standards and Procedures Workgroup Update Chair, Follow up & Treatment Workgroup  11:25 – 11:45 AM Committee Discussion  11:45 – 12:45 PM LUNCH  12:45 – 1:00 PM Prioritizing 2018 Workgroup Activities  Clinical and Public Health Impact of SCID Screening  Clinical and Public Health Impact of SCID Screening  Clinical and Public Health Impact of SCID Screening  Adrienne Manning Division Director, Newborn Screening Connecticut Department of Public Health Laboratories  Lisa Kobrynski, MD, MPH Associate Professor of Pediatrics Marcus Professor of Immunology Section, Allergy/Immunology  Section, Allergy/Immunology  Joseph Bocchini, MD			Resources and Services Administration		
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